ChildAIDS

Issue No.2:
Summer 1993
ISSN 0969-4048

NEWSLETTER OF THE NATIONAL FORUM ON AIDS AND CHILDREN

NEW EUROPEAN FORUM

In May, a three-day symposium on the needs of children and families affected by HIV took place in Italy. The symposium brought together thirty-five HIV specialists from eight European countries, including professionals with backgrounds in medicine, social work, and education, as well as a HIV positive mother. It was organised by the Institute of Child Health and the National Children's Bureau, with funding from the Wellcome Foundation's Positive Action Programme.

The consensus at the symposium was that a European Forum should be established to help coordinate national and international initiatives in this area. The Forum's objectives will include:

- Undertaking research to identify the needs of children and families.
- Facilitating the sharing of experience and the development of models of good practice.
- Working towards removing the stigma associated with HIV.
- Encouraging the inclusion of HIV information and awareness as a part of all sex education programmes.

Planned national projects include developing training programmes for teachers and social workers in Italy; preparing schools to receive HIV affected children in Romania; and setting up Non-Governmental Organisations to address the needs of children affected by HIV in Spain and Portugal.

Professor Catherine Peckham of the Institute of Child Health commented: *"Traditionally the focus has been on the person infected with HIV, and has concentrated on medical care. But for every child or parent infected with HIV, there are surrounding family members who are affected. I believe that setting up this Forum, which can use the experiences of so many countries, is an exciting step forward that will draw together the medical, social and education services and improve the ways in which we meet the needs of children affected by HIV".*

WORKING ON CHILDREN'S RIGHTS

The National Forum on AIDS and Children's new working group on children's rights met for the first time in June. It includes representatives of a number of agencies caring for children as well as specialists on children's rights, and is chaired by Hereward Harrison from ChildLine UK.

Its first task will be to identify what rights children have - or should have - in relation to a whole range of areas relevant to those affected by HIV, including:

- The right to healthcare and other necessary services.
- The right to services appropriate to age, sex, culture, etc.
- The right to consent to, or refuse, treatment.
- The right to consent, or refuse, to take part in clinical trials.
- The right to consent to, or refuse, an HIV test.
- The right to information.
- The right to confidentiality.
- The right to privacy.
- The right to education.
- The right to advocacy.
- The right to live free from discrimination.
- The right to normal life experiences.
- The rights of children as carers.

These will be looked at in the context of their status in UK and international law, and in addition,

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NATIONAL FORUM ON AIDS AND CHILDREN

The National Forum on AIDS and Children brings together organisations concerned with children infected or affected by HIV, from both the voluntary and statutory sectors.

The Forum aims to promote the interests and welfare of children and young people in relation to HIV/AIDS issues by:

- *promoting an effective voice for children.*
- *providing a national resource and data-base.*
- *disseminating information about good practice.*
- *promoting research and training.*
- *identifying un-met needs and promoting service development.*
- *campaigning and lobbying, representing members' views to government, media and outside bodies.*

ChildAIDS, the newsletter of the National Forum on AIDS and Children, is published quarterly. Views expressed in the newsletter do not necessarily reflect those of the Forum as a whole.

Contributions of articles, materials for review, or any relevant information, are welcomed and should be sent to the editor, **Neil Orr**, at the following address.

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Published for the National Forum on AIDS and Children by:

NATIONAL CHILDREN'S BUREAU
The powerful voice of the child

Registered Charity No. 258825

WORLD NEWS

□ UGANDA

HIV/AIDS has already had a dramatic impact on children in Uganda, and it has been estimated that by 1996 there could be over half a million children orphaned as a result of the epidemic. TASO (The AIDS Support Organisation) has two projects for children: the AIDS Challenge Youth Club and the Child Support Scheme. The AIDS Challenge Youth Club (ACYC) was established by a group of young people whose parents or close relatives are living with or have died of AIDS. Young people aged 13 to 25 meet regularly to share experience and ideas, seek AIDS information, give practical assistance to others in affected families, and play games.

TASO's Child Support Scheme aims to assist children from affected families with their education. According to TASO, *"Many children return home to sick parents and become the carers, returning to school the next day hungry and tired, their ability to learn lost to their poverty"*. Other children have to drop out of school altogether, their families no longer able to afford school fees. The Child Support Scheme provides financial support to enable access to primary education, though with over 19,000 dependant children of primary school age registered at TASO's seven local centres, it is not possible to support all the children in need.

TASO are developing other initiatives with children. In a letter to the National Forum on AIDS and Children, TASO's Marble Magezi notes that *"Material support has taken high precedence leaving out psychological support to these children"*, and that TASO would welcome contact with organisations with experience of such psychological support.

Marble Magezi (Public Relations Officer), TASO, Plot No.21 Yusufu Lule Road, P.O. Box 10443, Kampala, Uganda.

□ USA: NEW HIV TEST

US researchers have developed what they say is a *"rapid, simple and relatively accurate"* technique for diagnosing HIV in newborn babies.

Although *"the anxiety of parents... and the clinical benefit that accrues from early intervention make a rapid, early diagnosis of neonatal HIV infection important"*, this is difficult at present. The standard HIV antibody test cannot give a definite diagnosis in the first year of life. Other tests can give an earlier diagnosis, but *"are expensive, time-consuming, and impractical for screening large populations of newborns"*.

The new technique involves treating blood samples with glycine hydrochloride, making possible the detection of the HIV protein p24. In early trials, the test was largely successful in correctly identifying infected and uninfected children in the first three weeks of life. The authors of the study stress that *"Additional testing of the technique and confirmation of the initial results in other laboratories are necessary before the technique is adopted widely in neonatal HIV diagnosis"*.

Miles, SA et al (1993) Rapid serologic testing with immune-complex-dissociated HIV p24 antigen for early detection of HIV infection in neonates, *New England Journal of Medicine*, 297-302, Feb 4

UK NEWS

□ HIV Education in Schools

The Department of Education has issued a draft circular on Sex Education in Schools. The section on HIV education states that pupils are required to learn about the effects of HIV at Key Stage 3 (aged 14), and that *"Schools should also be prepared to respond to questions about HIV and AIDS from younger pupils"*.

It also suggests that *"schools should warn pupils of the health risks of casual and promiscuous sexual behaviour - whether heterosexual or homosexual - and of the dangers of drug abuse"*. No mention is made of the fact that is particular sexual acts (unprotected intercourse) rather than the type of relationship that poses a risk. Nor is any guidance given on helping young people to make decisions about reducing their risks.

Concern has also been expressed about the draft's completely negative comments on homosexuality, and its suggestion that teachers giving contraceptive advice to under-16s could be committing a criminal offence.

Meanwhile the Government has indicated that it may accept an amendment to the Education Bill in the House of Lords giving parents the right to withdraw children from sex and HIV education lessons.

Details of the Draft can be obtained from: Mr A B Thompson, Department for Education, Sanctuary Buildings, Great Smith Street, London SW1P 3BT (tel. 071 925 5497).

□ Life Education Centres

Life Education Centres are about to launch an AIDS/HIV pack for work with 9 - 11 year olds based on their interactive, discussion-based programmes with this age group. Part-funded by the National AIDS Trust, the pack aims to explore choices in preventing ill-health, develop an understanding of HIV, and generate discussion about the implications of HIV in today's society.

A parallel objective is to explore and develop attitudes of support and tolerance towards those affected by HIV. This will include guidance to equip teachers to deal with situations where a child in the group may be known to the educator to be affected by HIV, or may disclose this information during or after a session. In preparing this, LEC are keen to consult with those who have experience of addressing these situations.

Contact: Pamela Hall, Life Education Centres, 10 Southwick Mews, London W2 1JG (tel. 071 706 8966).

□ HIV and Older People

Age Concern Greater London have launched a new report, *A crisis of silence: HIV, AIDS and older people*. The report highlights the issues facing older people as grandparents of children affected by HIV. They have a positive role to play in supporting their extended family through a period of crisis; but resuming a parenting role in later life may be unwelcome or burdensome. The impact on children of caring for older relatives is also an under-researched issue.

More generally the report focuses on the needs of older people in relation to HIV, often assumed to be *"a territory of the young"*, even though 11% of people with AIDS are aged 50 or over.

Details from: Tara Kaufmann, AGCL, 54 Knatchbull Rd., London SE5 9QY (tel. 071 737 3456).

Statistics Update

- By April 30 1993, there had been 500 reports of children being born to HIV positive mothers in the UK (270 in the Thames Regions, 91 in the rest of England, Wales, and N. Ireland, and 139 in Scotland). Of these, 180 are known to be infected, 152 are uninfected, and 168 are of indeterminate status.

In addition, 270 children (aged 14 or under) in the UK became infected with HIV via infected blood or blood products. 194 of these are now aged 15 or over.

As of 31 January 1993, 64 HIV-infected children had died.

National Study of HIV in Pregnancy, June 1993; *Public Health Laboratory Service*, 26 April 1993.

- In Scotland, where HIV infection is often related to injecting drug use, numbers of children born to infected mothers have fallen since 1989. In England and Wales numbers are increasing; nearly half of the HIV+ mothers here were apparently infected abroad, particularly in sub-Saharan Africa.

Anonymous neonatal screening suggests that in south-east England, only 17% of infected pregnant women are known to the obstetric services. This suggests that a significant number of children are being born to mothers who are unaware that they are infected with the virus.

Rates of breastfeeding were 5% in women who knew they were infected, compared with 41% in women whose infection was recognised later. This is important, as breastfeeding increases the risk of HIV transmission.

Ades, AE et al (1993) Vertically transmitted HIV infection in the British Isles, *British Medical Journal*, 1296-9, 15 May

- In the United States up to the end of 1992, there had been 4,249 reported cases of AIDS in children under 13, and 946 in young people aged 13-19.

Centers for Disease Control and Prevention, February 1993.

AZT AND

AZT continues to make the headlines. Here Neil Orr provides a brief review of AZT and children, while below Diana Gibb and Lynda Harper describe the PENTA 1 trial.

AZT (zidovudine) was the first drug to be licensed for the treatment of AIDS, in March 1987. In May 1990, its use in HIV-infected children over three months old was also approved. Today, a sometimes emotive debate continues over the benefits or otherwise of the drug. One anti-AZT group calling itself Gays Against Genocide, has even picketed Great Ormond Street hospital over its participation in the PENTA-1 trial (see below).

Studies have suggested that AZT may improve survival in adults with AIDS, and it also seems to be effective in treating the effects of HIV on the brain. More controversially its use was extended in 1990 to symptom-free people with HIV, after two US studies seemed to show that AZT might delay the progression to AIDS. These trials were stopped before any long-term assessment could be made of the drug.

CONCORDE: The benefits of early intervention have now been called into question by the European Concorde trial which followed 1,749 people over three years. Preliminary results of the Concorde trial[1] seem to show no significant benefit for asymptomatic individuals in taking AZT. Survival rates were similar in those taking AZT from the start of the trial, and in those taking the placebo before switching to AZT at the onset of ARC or AIDS. In both groups 18% progressed to AIDS or died. On the other hand, the trial did not show that AZT was harmful: there was a low incidence of serious side effects.

CHILDREN: If the picture is confused in adults, it is even less clear in children. Trials that have been completed with HIV positive children, whether with symptoms or not, have tended to be of limited duration, on a much smaller scale than in adults, and have often not been placebo-controlled (meaning there is no control group of children not taking the drug to make comparisons with).

One of the most significant trials, ACTG 043[2], looked at 88 children with advanced HIV disease taking AZT over a period of up to 90 weeks. The children gained weight, and there also appeared to be an improvement in cognitive function. Another small study also showed improvements in neurodevelopmental abnormalities[3].

SIDE EFFECTS: The main reported side effect of AZT in children has been anaemia. In the ACTG 043 trial mentioned above, 26% of children suffered from (apparently) drug related anaemia, most of whom required blood transfusions. These children were already seriously ill however, and AZT seems to be less toxic when taken before the onset of advanced HIV disease.

Other side effects reported in some adults, such as nausea, fatigue, and headaches, have not so far been shown to be a serious problem in children. However these may be difficult to evaluate in younger children unable to articulate how they are feeling.

THE PENTA 1 TRIAL

by Diana Gibb* and Lynda Harper*

In uncontrolled studies zidovudine (AZT) has been shown to improve well-being and weight gain in children with symptomatic HIV disease and AIDS. In particular, children with HIV disease of the brain (encephalopathy) show improvement.

AZT is widely used in children with symptoms of HIV disease. The situation for children with few or no symptoms is unclear and paediatricians in different centres and countries start AZT at different times in the course of the infection. To date there have been no trials to establish when AZT should be started in children with HIV infection.

The PENTA 1 trial is only for children with definitely proven HIV infection. The trial aims to determine whether early treatment with AZT is more effective in delaying progression to AIDS and prolonging life than treatment which is begun only when symptoms are present. It also aims to evaluate the toxicity of long-term AZT treatment in children and to study the development of resistance to the drug. Side effects to AZT seem to be less common in children than in adults, and in both any side-effects are less frequent in early HIV infection.

The PENTA 1 trial is double blind and placebo controlled. This means that children have an equal chance of receiving AZT (in a children's dose depending on body size), or matching placebo syrup. They are followed regular, especially in the first three months, to monitor for any problems.

Any child may be transferred to AZT if he/she develops symptoms or if for other reasons, eg rapidly falling CD4 counts, the paediatrician feels that AZT is definitely indicated. The endpoints for the trial are progression to AIDS or death, and all children will be followed until at least the end of the trial.

The PENTA 1 trial hopes to include 400 children with vertically acquired HIV infection from across Europe. Recruitment started in the autumn of 1992, and so far children have been recruited from 16 centres in the UK, France, Italy, Belgium, Netherlands, Spain and Germany. Centres in ☞

(cont. p.5)

CHILDREN

There are still many unanswered questions about AZT and children: What are the benefits and disadvantages for children taking AZT in the long term? Does AZT make a significant difference to survival in children with AIDS? Can early intervention with AZT slow down the progression to AIDS or otherwise benefit children with mild or no symptoms? Should all children born to HIV+ mothers be given AZT at birth, as has occurred in the US, even if most of them will be uninfected with HIV?

In many cases it has simply been assumed that the results of adult studies can be applied to children. For instance, a US trial of AZT in children with HIV and mild symptoms (ACTG 052) was stopped prematurely in 1989 after adult trials appeared to support early intervention with AZT.

NEW TRIALS: More rigorous trials in children might answer some of the questions. In addition to the PENTA 1 study, there are other trials of AZT in children in progress or due to start shortly in the US. ACTG 182 plans to look at the efficacy of AZT in infants below nine months of age with HIV infection and no symptoms. ACTG 128 is comparing high and low doses of AZT in children with mild symptoms (but not with AIDS).

Another trial (ACTG 152) is comparing the effects of AZT and the drug ddI in symptomatic children, as well as looking at the effects of taking the drugs in combination.

INFORMED CONSENT: Particularly in view of our uncertain knowledge about AZT in children, it is important that parents and children (when of sufficient understanding) are provided with clear, balanced, and independent information about the drug. As part of its work on children's rights, the National Forum on AIDS and Children will be looking at the question of informed consent to drug treatments and trials[4], and debate on this is to be welcomed.

It is important though that such a debate should be carried out in a way that respects the intelligence and right to privacy of children and families affected by HIV. The use of emotive language such as *"genocide"* and *"murder"*, and pickets of clinics with the associated media presence, can cause distress to families and discourage them not only from AZT but from accessing a wide range of much-needed health care services for children.

Sources:

1. Aboulker, J-P and Swart, AM (1993) Preliminary analysis of the Concorde trial, *Lancet*, 889-90, Apr 3.

2. McKinney, RE et al (1991) A multicenter trial of oral zidovudine in children with advance HIV disease, *New England Journal of Medicine*, 1018-25, Apr 11. The names of US trials (ACTG 052 etc.) are those assigned by the AIDS Clinical Trials Group, which co-ordinates much AIDS research in the US.

3. Pizzo, PA et al (1988) Effect of continuous intravenous infusion of zidovudine (AZT) in children with symptomatic HIV infection, *New England Journal of Medicine*, 889-96, Oct 6

4. *AIDS Treatment Update* have produced an excellent new booklet called *Clinical trials: information for people who are thinking about joining a trial.* It includes advice on how trials work, their possible benefits and risks, etc. Free single copies can be obtained by sending an A4 envelope with a 45p stamp to AVERT, 11 Denne Parade, Horsham, West Sussex, RH12 1JD.

(PENTA 1 cont.)

Switzerland, Ireland, Sweden, and Portugal as well as Canada will shortly be joining.

The trial has been set up under the auspices of PENTA (Paediatrics European Network for Treatment in AIDS), funded by the EC, and is being jointly co-ordinated by the MRC HIV Clinical Trials Centre (UK) and the Service Commun 10 INSERM, Paris.

The Penta 1 trial is similar to the Concorde trial of early AZT in asymptomatic adults (see above article). However, HIV infection in children differs from that in adults in both the incubation period and the illnesses associated with the disease. It is also possible that early therapy could play a greater role in children because of the interaction between the virus and the developing immune system.

Given these differences and the importance of the question about when to start anti-HIV therapy in children, the PENTA Steering Committee, the MRC Scientific Board, and paediatricians across Europe have agreed that this important study should continue. The low toxicity of the drug in the Concorde study was an additional reason to continue. This will be kept under careful review, in the light of other studies. An independent committee will review both this and the progress of the trial at regular intervals.

As new drugs for HIV infection become available it is important that they are evaluated in children as well as in adults. The number of children with HIV infection in any one European country is small, hence the network of centres being developed through the Penta 1 trial will be invaluable for evaluating new treatments. Trials of combination anti-HIV therapies are being planned or starting through this network of paediatric centres.

* The Principal Investigator in the UK is Dr Diana Gibb, Senior Lecturer in Epidemiology/ Consultant Paediatrician at the Institute of Child Health /Hospital for Sick Children, Great Ormond Street, London.

Lynda Harper is the Data Manager for the PENTA 1 trial at the Medical Research Council HIV Clinical Trial Centre. For further information telephone the MRC on 071 351 8003.

A CHILD'S RIGHT TO KNOW?

As part of its ongoing work on children's rights, the National Forum on AIDS and Children recently discussed the question of the child's right to know about their HIV status. The discussion was introduced by Les Rudd (National AIDS Trust), Diane Melvin (St Mary's Hospital), and Rachel Hodgkin (National Children's Bureau). Neil Orr summarises the results of the discussion:

Why should children be informed?: Children are able to cope with adversity, provided they are properly involved and informed. Giving children appropriate information helps them to have a sense of control, gives them time to prepare for illness, and explains confusing or disturbing events (e.g. clinic visits, tests). It also enables them to make informed decisions about treatment, participation in clinical trials, etc. (in this sense the child's right to know underpins many other rights they may have). If children aren't informed they may fantasize about what is happening to them, with their fantasies becoming more frightening than the reality of their situation.

What should children be told?: There is no single correct way of informing children that is appropriate in all circumstances. Children need to be given clear, correct, and truthful information using developmentally appropriate language. The level of detail will need be tailored to the individual child. Informing children should not be seen as a one off event, as children's understanding develops over time.

> ***"telling a child can make living with HIV disease more difficult. Alternatively, not telling them denies a child an opportunity to develop adaptive behaviour and explore unspoken fears and anxieties."***
>
> Naomi Honigsbaum (1991), HIV, AIDS and Children

The current situation: The question of the child's right to know creates very real dilemmas for those working with children with HIV. Some parents decide that they will not inform the child until the child becomes ill, even though it may be at this point that the child is least able to cope with the news. Other parents have refused permission to inform even when the child is seriously ill, distressed, and asking difficult questions. In another case a young person who knew they had HIV was not informed of their AIDS diagnosis at the insistence of a parent. These situations have occurred with older children, even in some cases over the age of 16. Young people can feel very bitter when they discover that they have been kept in the dark in this way.

In practice, professionals will not inform children about their HIV status without their parents' consent, although they may tell the parents that they are not prepared to lie to children if asked a direct question. They try and work with parents, encouraging them to inform their children. Recognising that parents are usually motivated by a wish to protect the child, however misguided they may be about the best ways of doing this, they seek to persuade them that disclosing this information is in the child's best interest. They do not always succeed in persuading the parents however.

The legal situation: While recourse to the law might generally be inappropriate to settle this question, all those working with children need to be aware that in some circumstances children, or professionals acting on their behalf, may be able to take action to gain access to information without the parents' consent.

A general principle of the Children Act 1989 and its regulations is that children should be kept informed about what happens to them. More specifically, under the Access to Health Records Act 1990, children under 16 may apply for access to their health records, which will be granted if the holder of the records is satisfied that the child fully understands the import of his/her application.

The European Court has ruled that in some cases article 8 of the European Convention on Human Rights, which deals with the right to privacy, gives individuals the right to see information being held about them. This ruling was made in the Gaskin case, where a young person succeeded in gaining access to social services records from his childhood. There is no lower age limit to the provisions of article 8.

The way forward: Children's rights to information are generally mediated by adults who can refuse access on the basis of protecting the child's welfare. It is important to go beyond this rights/welfare dichotomy, and to acknowledge that in many circumstances the child's welfare is best served by recognising their right to be informed.

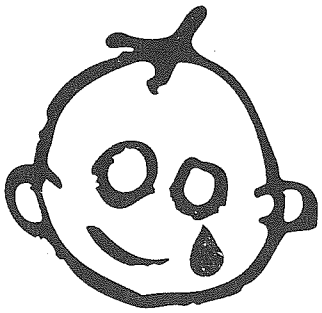
Where professionals are working with a whole family, there may be a danger of them colluding with the parents in order to avoid conflict, marginalising the rights of the child within the family. Professionals need to act as advocates for the children's rights in this situation.

An increasing number of people believe that in some circumstances children have an absolute right to information about their HIV status, ultimately even if parents oppose disclosure. This does not mean routinely telling children that they have HIV. In fact it is not a question of telling children but of developing ways of working which enable children to be in control of the process of finding out, to be listened to, and generally to participate in an informed manner in all that affects them.

PUBLICATIONS

□ **HIV and AIDS in Children: a guide for the family** - R. Lwin, C. Duggan, D. Gibb (Hospitals for Sick Children, 1993).

Written by members of the Great Ormond Street HIV team, this booklet is aimed at parents of children infected with HIV. Clearly written and well designed, it includes 48 pages of information on testing, symptoms, treatment, and many other issues.



Guidance on talking with children is included, with the authors suggesting that *"Deciding when and how to tell children is not easy but keeping secrets from them is rarely the best solution"*.

Advice is also given on preparing children for going to hospital: *"Preparing your child beforehand through talking, reading and playing can help your child understand and feel more relaxed about his or her clinic visits"*.

Copies of this booklet are being distributed by AVERT, 11 Denne Parade, Horsham, West Sussex RH12 1JD (tel. 0403 210202), price £1.

□ **AIDS and HIV - information for foster carers** (National Foster Care Association, 1993).

This 12 page booklet, which replaces an earlier publication in the NFCA's Signpost series, *"is designed to provide general information for all carers"*. It includes information on testing, confidentiality, hygiene, and other areas, and looks at some of the particular issues for foster carers.

The NFCA is working on another publication which will deal with training and advice for those caring for a child who is known to have HIV.

Details from: NFCA, Leonard House, 5-7 Marshalsea Road, London SE1 1EP.

□ **Briefing on the Children Act and HIV Infection: a guide for workers in the field** (Terrence Higgins Trust, 1993).

This useful briefing provides a summary of the main provisions of the Children Act, with examples of ways in which it may affect children and families with HIV or AIDS.

In one recent case a court ordered that two young children in local authority care should be tested for HIV, against the wishes of the local authority concerned. The relevant section 38(6) of the Children Act provides that *"Where the court makes an interim care order, or interim supervision order, it may give such directions (if any) as it considers with regard to the medical and psychiatric examination or other assessment of the child"*.

Details from Terrence Higgins Trust Advice Centre, 52 Gray's Inn Road, London WC1X 8JU (tel. 071 831 0330). For a report of the above case, see *New Law Journal*, June 4 1993, p.814.

□ **Placement needs of children affected by HIV** (National AIDS Trust, 1993).

Report of a seminar held at the Thomas Coram Foundation in London in January 1993. Contents include perspectives from support groups (Positively Women, Blackliners, and Positively Irish), and a discussion of the issues for refugee families.

Available from National AIDS Trust, 6th Floor, Eileen House, 80 Newington Causeway, London SE1 6EF, price £3.

ALSO OF INTEREST...

Help starts here: a guide for parents of children with special needs (Council for Disabled Children / National Children's Bureau, 1993).

A signpost to the wide range of statutory, voluntary and professional services which can help parents and children.

Details from Book Sales, National Children's Bureau, 8 Wakley Street, London EC1V 7QE (tel. 071 278 9441).

A benefits guide for children and young people with disabilities (Disability Alliance ERA, 1992).

A comprehensive guide for parents of children with disabilities about benefits, including the new Disability Living Allowance.

£4 from DAERA, 1st Floor East, Universal House, 88-94 Wentworth Street, London E1 7SA.

Children who care: inside the world of young carers - Jo Aldridge and Saul Becker (Loughborough University, 1993).

Using young carers' own words, this report explores the reality of children caring for sick or disabled relatives in the home. The expressed needs of young carers for support and information are identified, with the authors arguing for a rights based approach to meeting these needs.

£7.99 from Nottinghamshire Association of Voluntary Organisations, 1 Byron Street, Mansfield, Notts., NG18 5NX.

Children first: a study of hospital services - the Audit Commission (HMSO, 1993).

Finding that the principle of *"child and family-centred care"* is often not implemented in practice, this report argues that the root problem *"is that clinicians, managers and other staff do not give sufficient attention to the needs of children and their families"*. It recommends written policies *"to ensure that requirements for child and family-centred care are understood by all those involved and applied consistently"*.

COURSES AND CONFERENCES

27 - 29 July 1993: **AIDS and HIV: working with older children and teenagers**, London. Three day course at the London Lighthouse, 111-117 Lancaster Road, London W11 1QT (tel. 071 792 1200).

September 1993 - : **ENB Course 934: Children, families and HIV**, London. 17 day course over four month period at Charles West School of Nursing, Great Ormond Street. Details from Gillian Dransfield (course tutor), 071 829 8676, ext. 5835.

7 - 10 September 1993: **2nd International conference on HIV in children and mothers**, Edinburgh. Organised by the Paediatric AIDS Resource Centre. Details from PARC, 25 Hatton Place, Edinburgh EH9 1UB (tel. 031 668 4497).

16 September 1993: **Children affected by HIV/AIDS: Who cares for the child?**, Cambridge. One day seminar organised by British Agencies for Adoption and Fostering, South Regional Centre. Details from Pauline Thorbourne, BAAF, 11 Southwark Street, London SE1 1RQ (tel. 071 407 6712).

14 October 1993: **Support for families of women and children with HIV**, London. Organised by the RPMS Institute of Obstetrics and Gynaecology with the Terrence Higgins Trust. Details from: Course and Symposium Office, RPMS Institute of Obstetrics and Gynaecology, Queen Charlotte's and Chelsea Hospital, Goldhawk Rd, London W6 0XG (tel. 081 740 3904/3922).

21 October 1993: **National Forum on AIDS and Children**, quarterly meeting: Meeting the needs of older children and young people affected by HIV (venue to be arranged).

WEST LONDON SERVICES

A report on HIV and children's services in West London was launched at a conference at the end of the May. Written by Dee Donnelly, it reviews services in Westminster, Hammersmith and Fulham, and Kensington and Chelsea local authorities, as well as Parkside and Riverside health authorities.

The report makes recommendations for each of these agencies, as well as for the local voluntary sector. A central emphasis is on the need to *"develop cross-boundary working practices among service providers, for example, between adults' and children's services"*.

To avoid duplication of work and confusion for families, Dee recommends that multi-agency assessments need to be developed, with "*an identified key worker responsible for overall coordination*".

As part of the research for this report the author consulted with service users. Among the issues that arose in discussions with parents was a reluctance to access social services for fear of losing parental responsibility, confusion about how the system works, and feelings of exhaustion from trying to access services.

The report stresses the importance of incorporating the views of service users in all children's service developments, although it is recognised that ascertaining the views of the children themselves can often be difficult, chiefly because *"many children remain unaware of either their own or their parents' HIV status"*.

HIV and children's services: have we got it right? is available from Room 234, Town Hall, Hornton Street, London W8 7NX (tel. 071 937 5464, ext. 2437).

WORKING ON CHILDREN'S RIGHTS

(continued from page one)

recommendations will be made about rights not presently recognised in law. Aware of the limitations of rights which exist only on paper, the group will also consider what practical steps need to be taken to make these rights a reality for children and young people.

The working group plans to produce a document on the rights of children affected by HIV later in the year, clarifying what rights children have and generally encouraging debate. It is to be hoped that this document will not be seen as a one off exercise, but will become part of a process in which the rights of children and young people are accorded a central position by all agencies working with HIV.

Preliminary results of the group's work will be presented in a poster display at the International Conference on HIV in children and mothers, in Edinburgh in September.

■ The Forum's **Practice Standards** working group will shortly be circulating a draft document. Its aim is to make traditionally adult-centred HIV agencies aware of some of the considerations entailed in working with children and families.

For further information about the working groups contact Huw Meredith at the National AIDS Trust, 071 972 2845.